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ABSTRACT

This booklet is designed to assist those who may be in a situation of consoling a person with mental retardation who has either just lost a parent or friend or is near to someone whose death is imminent. The first part of the booklet explores why it is important that people with mental retardation know about the death. It provides guidance on how to explain that a death has occurred and what is possible to expect in terms of the individual's grieving. Information is then given on what parents and others can do to help the individual to grieve a loss and steps to take in teaching about death that will prepare people with mental retardation about the inevitable deaths of family members and friends. Last, the booklet uses a question and answer format to provide guidance on various situations regarding death and grieving. Community resources and other materials are listed at the end of the booklet. (CR)

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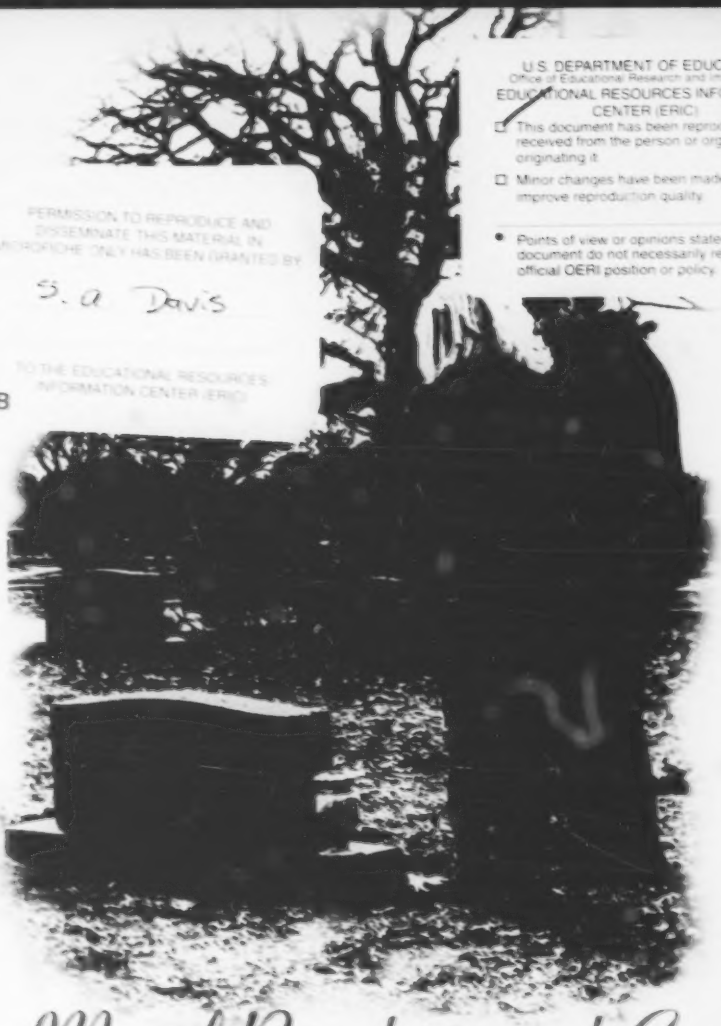

Mental Retardation and Grief following a Death Loss.

Information for families and other caregivers

The Arc

a national organization on mental retardation

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Mental Retardation and Grief following a Death Loss

Information for families and other caregivers

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January 1998

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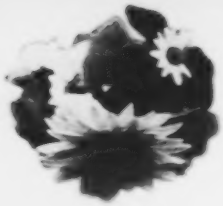


Mental Retardation and Grief following a Death Loss

Information for families and other caregivers

Foreword

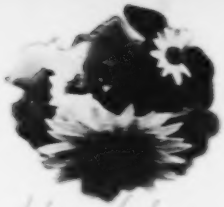
Returning to my hotel room from a meeting of the Board of Directors of The Arc in 1996, the red message light was blinking. "Please, call your daughter, Becky. Tim is dead." Thirty-two-year-old Becky had gone to school with him and lived in a group home with Tim for a year. They had remained good friends after each moved into an apartment. With some apprehension, I picked up the phone. Within the next week, we attended the wake and the funeral together. Six months later another of her friends supported by the same agency died. And we attended another funeral. By experiencing the loss and grief of other deaths together, Becky will be better able some day to work through the loss and grief when I die. This became part of my planning for her future as we talked about the fact that some day I too would die. We discussed what that would be like.

People with disabilities, like the rest of us, cannot escape from experiencing the deaths of friends, families or surrounding staff. Nor can they escape the feelings of grief after a death. This booklet should help prepare for the day when a person with mental retardation experiences the death of a friend or loved one. I urge you to read it now and to keep it handy as a resource for the time when you must help a person with mental retardation through the loss and grief associated with death. I only wish that this booklet were at hand when I received the phone call about Tim's death.

Quincy Abbot
President
The Arc

Overview

This booklet was written to assist parents, friends, staff people and others who may someday be in a situation of consoling a person with mental retardation who has either just lost a parent or friend, or is near to someone whose death is imminent. Based on research and first-hand experiences, the booklet addresses what may be involved in telling someone with mental retardation about the death of a family member or friend, and then supporting the person though his or her individual grief. The first part of the booklet explores why it is important that people with mental retardation know about the death. As the person may not clearly understand what "death" means, and may not outwardly display or acknowledge grief, the booklet provides guidance on how to explain that a death has occurred and what to possibly expect in terms of the individual grieving. Information is then given on what parents and others can do to help the individual to grieve a loss, and steps to teaching about death to prepare people with mental retardation about the inevitability of family members and friends someday dying. Last, the booklet uses a question and answer format to provide guidance on various situations regarding death and grieving. Additional assistance, including community resources and other materials, are included at the end of the booklet.



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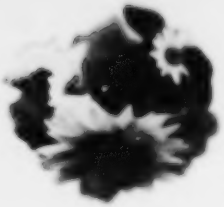
A number of individuals provided materials, resource lists and other information that aided in developing this booklet. Thanks to Ann McGuire, Nancy Kirchner, Linda R. Lamoureux and Kelly McLear for their assistance. Kelly Osmont's permission to use her poem is also greatly appreciated.

Last, staff of The Arc were instrumental in reviewing, editing, and overall production of this booklet. A big thanks to Sharon Davis, Ph.D., Rick Berkobien, Liz Moore, Michelle Schwartz, Jim Humphrey, Sue Eades and Ann Balson. We also appreciate Rosa Ingledue and Denise Pierce, staff person with NCE of The Arc, for assisting in the cover design of this publication.



Mental Retardation and Grief following a Death Loss

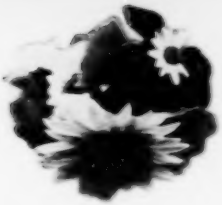
Information for families and other caregivers

Death — An Uncomfortable and Uncommon Subject

Perhaps you are the parent or sibling of an adult with mental retardation, or maybe you have a professional relationship with an adult with mental retardation, for example, you are a supportive residential staff member or a case manager. You are someone important in this person's life, someone to whom he or she comes for support and guidance. How will you handle the subject of the death of a loved one?

- Do you feel uncomfortable when you think of the subject of death?
- Do you ever worry that someone important in this person's family or circle of friends might die?
- Do you find it hard to imagine dealing with the death of a loved one yourself and, at the same time helping the person with mental retardation through this crisis?
- Do you avoid the subject of death because it seems too sad or overwhelming to think about?
- Do you feel you lack the knowledge or skills to be able to help an adult with mental retardation who has experienced the death of someone close?

If you answered "yes" to any of these questions, you are certainly not alone. Death is a topic that is usually avoided in this country. Few people receive any education or training about death or grieving. Yet all of us, if we live long enough, will likely



experience grief over the deaths of family members or friends. We learn from our experience. But we may wonder, is the experience different for an individual with mental retardation? We also may worry how we can help someone else, especially someone who may have difficulty understanding what is happening.

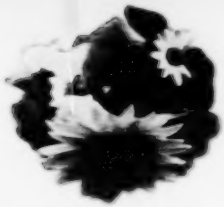
If you are uncomfortable with the subject of death, or are concerned or puzzled about how to help someone with mental retardation when a loved one dies, then this booklet was written for you. It is hoped that by reading this booklet, you will start to feel more comfortable with this topic and that you will find this information useful in your role as a support person for an adult with mental retardation.

To Tell or Not To Tell

There are several reasons for telling adults with mental retardation about the death of someone close.

- Death is a part of life. If we want to promote as normal a life as possible for people with disabilities, we cannot shield them from the truth. Helping them cope with the bad experiences that happen in life will be more successful than trying to shield them.

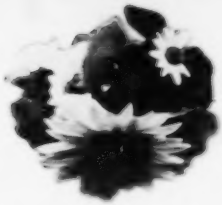
- Their thoughts may be worse than reality. If they are not told about the death, they will miss the deceased person, yet may not understand what has happened.



For example, they may think the person did not love them anymore and therefore has gone away, or they might think that a bad person has taken their loved one away, and that the bad person will come back to get them too.

- They may overhear others talking about the death or even read the obituary in the newspaper. They can feel anger, sadness, or think that their family considers them unimportant if they are left out when such significant events occur.

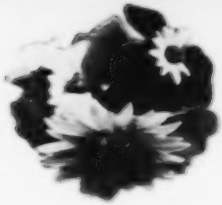
- They may have difficulty recovering from the absence of the person if they are denied the opportunity to talk about the loss and express their emotions.



Understanding the Concept of Death

In general, abstract concepts like death can be difficult for people with mental retardation to grasp. Thus, many people wonder what adults with mental retardation understand about death. There is no quick and easy answer to this question. People with mental retardation vary a great deal in their abilities to understand. Someone's understanding is influenced by his or her life experiences and the ability to think and reason. Something that one person may understand, another person may not comprehend at all. Sometimes it can be quite difficult to know exactly what adults with mental retardation comprehend, especially if they do not have strong verbal abilities.

Regardless of what an adult with mental retardation comprehends about death, we must remember that if a loved one dies, the person has experienced a loss. Even if the person does not understand death, he or she is likely to miss the person who died and would benefit from help in coping with the loss.



Telling an Adult with Mental Retardation That a Loved One Has Died

Telling someone that a loved one has died is always difficult. Following are a few suggestions to keep in mind when the person whom you are telling has mental retardation.

- Try not to delay the sad news. If the person is not told about the death soon after it occurs, there is a greater chance that he or she will hear about it accidentally from others, or will feel left out because others received the news first.

- Go to a quiet location where the person is likely to be comfortable.

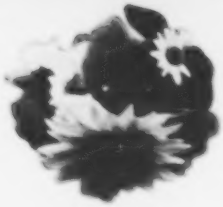
- Carefully choose your first sentence. For example, say, "I have some sad news to tell you."

- Be truthful.

- Use simple words that you think the person will understand. For example, use the word "die" rather than "passed away."

- Try to avoid phrases that can have more than one meaning. For example, say, "Your dog was hit by a car and died," rather than "Your dog went to sleep." Say, "Grandpa died" rather than "We lost grandpa."

- Give simple details that will help the person understand. Remind him or her about details that may have been seen



or heard earlier. For example, say, "Do you remember how your mom couldn't talk when we saw her yesterday and she slept a lot? That was because something bad happened in her brain. It is called a stroke. Your mother had another stroke today. The doctors tried to help her, but she was hurt too badly and she died."

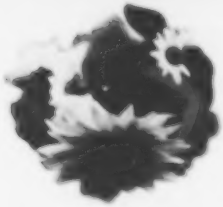
- Ask if the person has questions.

- If you are grieving too, do not try to hide your grief. Share your thoughts and feelings. Grieve together.
- Reassure the person that you or others will be available to help him or her.

Recognizing When an Adult With Mental Retardation is Grieving

How do you know when a loss has affected someone? How do you know when he or she is grieving?

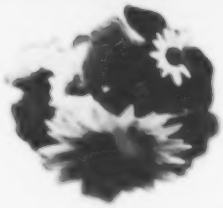
- **Expect a reaction** to the loss if someone close to the person has died. The reaction may not occur immediately; it may not be one that you thought would occur, but there is likely to be one. Someone may appear as if he has coped with the death, yet many months later, grief reactions will appear. It may take time before the reality of death sinks in. Over time, he realizes the loved one really will not be returning, and begins the grief process in earnest.



- **Talk to the person** about the death. Share your feelings. Ask how she feels -- she may be suffering in silence. Unless someone else brings up the subject, the adult with mental retardation may not do so. She may feel it is a taboo subject or that others would become upset if she brings up the subject. Yet, the person may have some unanswered questions, puzzling dreams, and a mixture of emotions that must be dealt with alone unless a caregiver offers help.

- **Be observant.** Listen to what the person says. Watch how he or she behaves. The person's actions may tell you more than his or her words. Some adults with mental retardation may not indicate through their words that they are upset. They may even try to reassure others that they are okay. Their behavior is likely to show their innermost feelings. Does the person's behavior match her or his words, (e.g., if the person says he or she is okay, do his or her actions also tell you that the person is okay)?

- **Become familiar with common grief reactions.** Does the person describe symptoms that seem to be grief reactions? Are some of the person's actions uncharacteristic compared to her typical behavior? For example, is someone much quieter

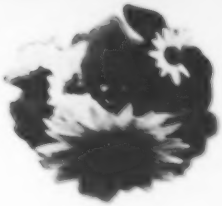


than usual? Is he spending more time alone? Are there unexpected angry outbursts? Is she not doing as well at work? Does the person have unexplained symptoms (e.g., headaches or stomachaches)?

Common Grief Reactions of Adults

Little research has been conducted regarding the grief reactions of adults with mental retardation, but an ever-growing number of descriptions from families and specialists indicate that adults with mental retardation have the same or similar grief reactions as all adults. Researcher William Worden reports the following common grief reactions for people in general. All of them are considered common or normal when they occur following a loss. Please note that every person will not have all of these feelings and reactions.

These grief reactions can be grouped into four



categories: the emotions we feel, the physical sensations we experience in our bodies, our thoughts, and our behavior.

Feelings

- sadness
- anger
- guilt
- anxiety
- loneliness
- helplessness
- shock
- yearning - pining for the person who died
- emancipation - freedom from the person's wishes or commands
- relief
- numbness

Physical sensations

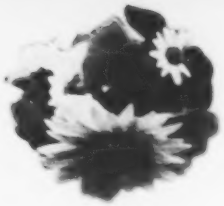
- hollowness in the stomach
- tightness in the chest
- tightness in the throat
- oversensitivity to noise
- depersonalization - feeling that things do not seem real
- shortness of breath
- muscle weakness
- lack of energy
- dry mouth
- fatigue

Thoughts

- disbelief
- confusion
- preoccupation - obsessed with thoughts of the deceased
- sense of the presence - feeling that the deceased person is nearby
- hallucinations

Behaviors

- sleep disturbances
- eating too much or too little
- absent-minded behavior
- withdrawing from others
- dreaming about the deceased person

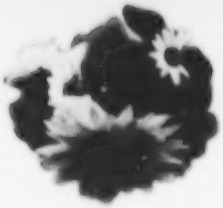


- avoiding reminders of the deceased person
- calling out the name of the deceased person
- sighing
- restless overactivity
- crying
- visiting places or carrying objects that are reminders of the deceased person
- treasuring objects that belonged to the deceased person

What is Normal?

This booklet and other printed materials on grief that can be found in book stores describe "typical grief." That is, they describe common experiences among grieving people in the United States. Grief reactions and experiences, however, can be very different from person to person, and still be considered "normal." There is no "right" way to grieve.

Many things can affect how someone grieves. Men may react differently than women. Young people may react differently than older people. Religious beliefs, personality, where someone lives, and his or her ethnic background can all influence how someone



expresses emotion. Grief is often expressed very differently from one culture to another. People of European descent may talk about their emotions while Chinese people tend to talk about bodily symptoms such as headaches or stomach problems. Japanese individuals and people with Anglo Saxon Protestant backgrounds tend to bear suffering in silence, while people from Hispanic backgrounds tend to openly express their pain. Values and beliefs differ among the 350 Native American tribes in the U.S.

, Not all people who share a similar background or ethnic group will grieve in the same way. For example, many black Americans grieve openly, readily showing their emotions; however, some grieve more quietly or in private.

People who try to understand and accept differences in beliefs, values, and expression of emotion are likely to become the most helpful to others.

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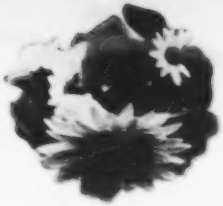


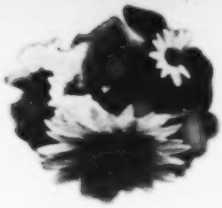
It Takes Time to Heal From a Death Loss

Grieving a death loss takes longer than many people think it will. The length of time it takes differs from person to person. In fact, it varies so much that several noted grief specialists do not offer guidelines for an average length of time. If the deceased was someone close, a person is likely to grieve for at least the first year following the death. For some people the death becomes more real the second year; they might describe themselves as feeling numb during the first year.

If someone is able to resume usual activities and the grief reactions decrease in intensity over time, he or she is considered to be recovering. Recovery occurs after a person has grieved, learned to live without the loved one and can focus his or her energy on other activities and relationships.

Grief can be triggered again even years after the death by events such as birthdays, holidays, and the anniversary of the death. Grief can also recur as someone reaches a milestone in life that he or she expected to share with the person who died; e.g., a graduation, a new job, or a new place to live. It is very normal for people to feel some sadness on these occasions. Usually, this grief does not last a long time.

Some adults with mental retardation seem to have strong grief reactions many years after the deaths of loved ones. They might bring up the subject, talk about the deceased loved one or cry in a manner similar to grief following a recent death. There could be several explanations for this behavior; two are described here. The person may not have fully healed from the loss when it occurred, and might benefit from assistance to complete the grief process. Another explanation is that the person's network of family and friends may be small; talking about the deceased loved one may help the person feel connected to the loved one through memories. If the behavior interferes with the person's enjoyment of life or daily activities, it is a good idea to consult a grief specialist for help.

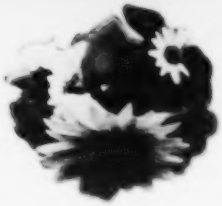


How to Help the Grieving Person

- **Be with the person.** Spend more time than usual with him. Let the person know that you care about him. He may worry that you or another loved one could die too. Try to reassure the person that someone will always be around to help him. If possible, talk about the people who can help in the future.

- **Talk about the death and the person who died.** Allow the person to talk often. Talking about it over and over again helps many people heal from their losses. Often, people find mutual support in sharing their grief with others who are grieving. Locate a peer, staff member or other individual who has recently lost someone and who would be willing to talk to the person. The individual with mental retardation might also benefit by taking part in a regular grief support group through a local hospice organization.

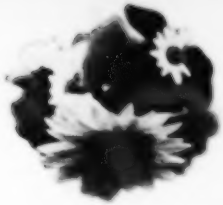
- **Share feelings.** Help the person express her feelings. If the person cannot talk about feelings, consider art projects such as drawing or painting. Ask the person to draw what she feels inside or thinks about.



- **Encourage the person to attend the visitation/wake and the funeral or memorial service.** Tell the person in detail what to expect. Talk about the casket, the body, flowers, music, people crying, and other things that he is likely to see or hear.

- **Try to prevent other losses.** It is hard for people to deal with more than one loss at a time. Try to keep life the same as much as possible. For example, it could be very difficult for the person who loses a loved one, a job, and her home all at the same time.

- **Allow the person to make choices.** The person may have an idea of what would help him feel better. For example, one person may want to return to work a day or two after a death; someone else may need to remain home for a week or two. Allow the person to make these kinds of decisions as much as possible. Some people with disabilities become confused or upset if they are given too many choices. If this is the case, help him make choices.



Teach About Death

One of the best ways to help is to teach or prepare an adult with mental retardation about death, before someone close dies. Following are some suggestions for teaching:

- Use simple words when you talk about death. Try to avoid words that have more than one meaning. (See the section titled, "Telling an Adult with Mental Retardation that a Loved One Has Died.")

- Teach by using examples in everyday life such as the death of a companion, animal or news stories about the death of a famous person.

- Use many examples over time. Do not assume that one serious talk about death is enough. There may be misunderstandings. Over time, you will be able to identify what the person has misunderstood and to provide correct information.

- Allow the person to see how you deal with losses in your life. Talk about small losses and how you cope with them. If someone whom you know dies, tell the person about it. If possible, take her to the funeral home and the cemetery. Describe what she will see before you go. Allow the person to see your emotions. Show and tell her how you cope with this loss.

- Allow him to show emotion. The person may deny that all people die, may show anger or fear, or may cry. Let him know that you understand the emotion. You might say, "I know that it's scary to think about death." or "I feel sad when I think about someone dying too."

- Encourage questions. Answer them honestly.

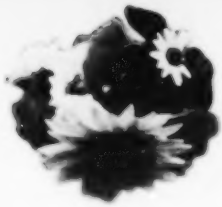
- Talk about stages of life: birth, childhood, adulthood, old age, death. Talk about unexpected death from illnesses, accidents or violent actions.

- Identify someone who could lead a class or group to talk about death and grief. Invite the person's friends and peers. They can then share their feelings and obtain accurate information together.

- Describe what is good about death. For example, someone who was suffering from a painful illness or accident will no longer feel pain. Talk about life after death if this concept is part of her religious beliefs.

- Help the person feel safe now. Talk about ways to prevent accidents, illnesses, or acts of violence. Name people who care about him and who can provide help in the future.

- Provide hope. Tell how people recover after losses. Describe how happy memories help people after someone dies.

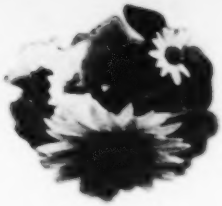


Questions and Answers

Following are questions similar to those asked by other caregivers when they were trying to help an adult with mental retardation. The answers may be helpful to you as you provide support to someone who has had a death loss. Please remember, however, that your situation may be different than those described, and may require a different approach.

Q. *My uncle has mental retardation. His roommate died a couple months ago. He doesn't talk about his roommate. Is it best if I don't bring up the subject either?*

A. Bringing up the subject will probably not cause your uncle to feel sad. If he is upset about his roommate's death, talking about it can help him express his feelings. However, he may be hesitant to bring up the subject. A suggestion is to offer him several opportunities to talk about the death. If he has difficulty talking about this death and his feelings, you might describe to him how you felt when a friend died and what helped you heal from the loss.

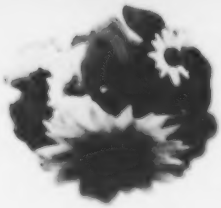


Q. *A friend of my client died. My client is teary a lot and cries readily. How can I help her to stop crying and have happy days?*

A. What your client may need most is to express her true feelings. As hard as it is to watch someone else grieve, allowing her to cry and talking to her about her friend and his death will help her more in the long run than if you try to distract her from the grief. Nature has provided us with some built-in relief. Grief tends not to be constant, instead it comes in waves. So even in the midst of her grief, you are likely to find that there are activities or events that she will enjoy. As she recovers from her sadness, she will have more and more days in which she is happy or satisfied.

Q. *My co-worker did not cry at his mother's funeral. He talked and even laughed with others at the funeral home. He has returned to work, and his work seems fine. Is it possible that he has already recovered from his mother's death?*

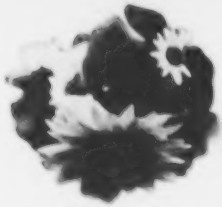
A. Your co-worker may be someone who grieves when alone, rather than in public. He may be learning his behavior from others around him who are "keeping a stiff upper lip." Or maybe he sees that others around him are upset, and he does not want to add to their



distress, so he hides his feelings. It is also possible that the reality of the death has not yet hit him. You may first notice grief reactions weeks or even months after his mother's death as he starts to realize that his mother will never come back.

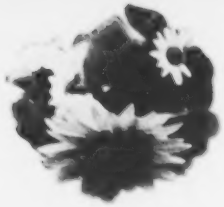
Q. *My sister with mental retardation refuses to look at pictures, talk or hear stories about our father who has died. Should I be firm and insist that she talk or listen? Will this help her recover?*

A. Talking about the death and the deceased person is an activity that helps people cope with a death and eventually heal from the loss. It is important to offer your sister opportunities to talk or listen. However, it is not a good idea for family and staff to try to force her to do something when she is not ready. As time goes on, she may be able to talk about your father. Yet, some people, including those without disabilities, choose never to talk about a loved one who has died. Watch your sister's behavior over time. It would be a good idea to consult a grief specialist if her behavior, work habits or personality change and remain different than before the death.



Q. *My son talks continually about his father's death. He repeats the same stories over and over. I frankly can't deal with this anymore. How can I get him to stop this behavior?*

A. Some people with mental retardation tend to perseverate; that is, they repeat words or sentences over and over again. This can be very annoying to family members or others who hear it continually. Sometimes a doctor prescribes medication or a professional develops a plan used by caregivers to reduce perseveration. It is important following a death loss, however, not to choose these alternatives too quickly. Many people who are grieving (not just those with mental retardation) talk about the death and the person who died over and over again; it helps them to eventually accept the loss. Your son may also feel that others are forgetting his dad. Repeating stories may be his way of keeping his father's memory alive. This is a very stressful time for both of you. Each of you may have different needs right now. Enlist the help of others. Arrange for some quiet time away from your son. Identify people with whom your son could spend some time. You may want to consider working with a grief counselor to obtain support for yourself and to learn about activities that could help your son cope with his dad's death.

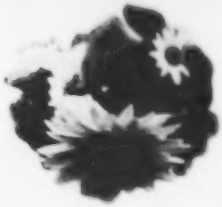


Q. *I am an adult family home provider for a woman with mental retardation. Her aunt recently died. She is very emotional about the death, but I don't understand her reaction since she wasn't close to her aunt.*

A. The woman's grief may be very real. Sometimes people feel a sense of connection to someone else, even though that relationship is not apparent to others. In fact, relationships with family members that have been less than satisfactory can be among the most difficult to grieve. The woman may also be worried that someone else close to her could die, or she may be afraid of her own eventual death.

Q. *My grandmother died and my sister with mental retardation wants grandmother's wedding ring. I am afraid that she will lose the ring. I don't know why she keeps asking for it.*

A. Many people feel comfort and a sense of connection to a deceased loved one by keeping an item that used to belong to the deceased person. Different items will have meaning for different people. One person may feel close through a piece of jewelry; someone else might treasure fishing equipment. Your sister seems to have a sense of something that will help her cope with her

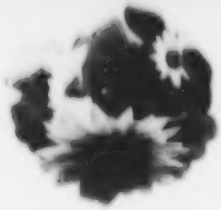


grandmother's death. Members of your family can decide if they are comfortable entrusting the ring to your sister. If it is not possible to give the ring to your sister, consider asking her if she might like another item that belonged to your grandmother.

Seeking Help for Grief

There has been a growing awareness that people would benefit from help as they grieve. Fortunately, in answer to this need, many supportive grief services have developed. Books, consultation, counseling and support groups are now readily available to most people. You do not need to be in acute crisis to receive help. It is available to anyone who wants compassionate support and understanding.

It appears there are few specialists experienced in helping adults with mental retardation who are grieving. However, many excellent clinicians and counselors are willing to help. One way to get help

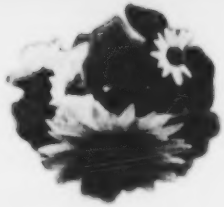


for an adult with mental retardation is to locate a grief specialist who will become a "partner" with you in helping the person with mental retardation. You can provide information about the person, such as past and present behavior, details about his or her relationship with the deceased person, and help in understanding the person if he or she has difficulty in speaking. The grief specialist can give you information about typical grieving and can work with the person who is grieving or can give suggestions for activities that may help the person express feelings and cope with the loss.

Many grief resources that are used by the general public can also be used by adults with mental retardation. Some people with mental retardation have participated meaningfully in grief support groups attended by the general public. Some grief books designed for children are also appropriate for adults, and can help explain death and grief in ways that adults with mental retardation may understand.

Following are people whom you can call for help following a death:

- Ministers, priests, rabbis, and other religious staff can help by involving the person with mental retardation, along with other family members, in the planning of a funeral or memorial service. He can also help explain



religious beliefs concerning death. It is important to respect the beliefs or religious background of the grieving person, if they differ from your own.

- Primary care physicians can help you figure out if the symptoms someone has relates to an illness or grief. She may also be aware of grief resources in your community.

- Grief counselors, psychiatrists, psychologists, and social workers practice in a variety of settings such as clinics, hospices, mental health centers, and private practice. Not all counselors or therapists are experienced in working with grief and loss issues. It is a good idea to ask about the background and specialty area of professionals, and choose one who has had training and experience in the area of grief and loss.

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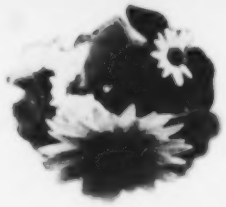


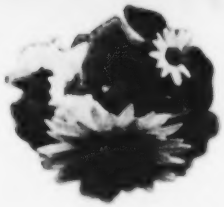
About the Author

Charlene Luchterhand, MSSW, is a certified independent clinical social worker living in Madison, Wisconsin. She has specialized in the areas of aging, developmental disabilities, grief and health promotion, and has provided outreach education for a variety of national, state and local audiences. Ms. Luchterhand is co-author of:

Helping Adults with Mental Retardation Grieve a Death Loss
by Charlene Luchterhand and Nancy Murphy

This book, published in 1998, describes grieving that is typical for people in general; gives information about grieving that is unique to adults with mental retardation; identifies how to locate qualified professionals for help; and suggests over 100 concrete ideas that can be used to help adults with mental retardation as they move through the grief process.

To obtain, contact:
Accelerated Development,
a member of the Taylor & Francis Group
1900 Frost Rd., S-101
Bristol, Pa. 19007-1598
1-800-821-8312



Other Written Resources on Grief and Mental Retardation

In Sickness and in Death
by Lotte E. Moise

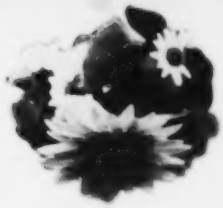
A short article written by the mother of a daughter with mental retardation. The article describes her daughter's experiences with the deaths of others and advocates that caregivers prepare people with mental retardation for sickness and death.

Published in 1978 by the American Association on Mental Retardation (AAMR) in Mental Retardation, 16(6), pp. 397-398.

Many university and local libraries carry AAMR's Mental Retardation.

Person-Centered Planning for Later Life: A Curriculum on Death and Dying for Adults with Mental Retardation
By H. Sterns, E. Kennedy-Hart, C. Sed, and E. Sutton.

A Project of the Institute for Life-Span Development and Gerontology, The University of Akron and the Rehabilitation Research and Training Center (RRTC) on Aging with Mental Retardation, Department of Disability and Human Development, University of Illinois at Chicago. (Anticipated completion date: fall 1998) For more information, contact the RRTC Clearinghouse on Aging and Developmental Disabilities, 1-800-996-8845 (V); 1-800-526-0844 (Illinois Relay Access)



Grieving Support Resources
By The Arc

A list of materials and other resources on people with mental retardation and death, dying and grieving support following a loss. 1998. For a copy, send your request and $2 for postage and handling to: The Arc of the United States, P.O. Box 1047, Arlington, Texas 76004.

There are also many books to help the general public, both children and adults, who are grieving. You may find some of them quite helpful. Hospices often have lists of books that others have found helpful. Some hospices even have lending libraries where you can borrow books. Your local chapter of The Arc may have articles and books on the topic. Also, local bookstores usually carry many books on death, loss, and grieving. You may want to scan a few to see if one or two seem especially appealing to you.

The author and The Arc of the United States hope that this booklet has helped you to feel more comfortable with the topics of death and grief, and that it has provided ideas that will help you support an adult with mental retardation. You can make a difference in the life of someone with mental retardation. The following poem may provide encouragement. Best wishes.

Please, See Me Through My Tears by Kelly Osmont

You asked, "How are you doing?"
As I told you, tears came to my eyes . . . and you looked away and quickly began to talk again. All the attention you had given me drained away.

"How am I doing?" . . . I do better when people listen, though I may shed a tear or two.
This pain is indescribable. If you've never known it you cannot fully understand.
Yet I need you.
When you look away, when I'm ignored,
I am again alone with it.
Your attention means more than you can ever know.

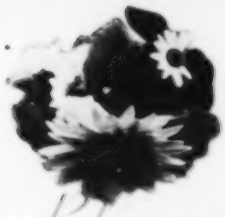
Really, tears are not a bad sign, you know!
They're nature's way of helping me to heal . . .
They relieve some of the stress of sadness.

I know you fear that asking how I'm doing brings me sadness . . . but you're wrong.
The memory of my loved one's death will always be with me.
Only a thought away.
My tears make my pain more visible to you,
But you did not give me the pain . . . it was already there.
When I cry, could it be that you feel helpless, not knowing what to do?
You are not helpless, and you don't need to do a thing but be there.

When I feel your permission to allow my tears to flow, you've helped me.
You need not speak. Your silence as I cry is all I need. Be patient . . . do not fear.
Listening with your heart to "how I am doing" relieves the pain, for when the tears can freely come and go, I feel lighter.
Talking to you releases what I've been wanting to say aloud, clearing space for a touch of joy in my life.
I'll cry for a minute or two . . . and then, I'll wipe my eyes, and sometimes you'll even find I'm laughing later.

When I hold back the tears, my throat grows tight, my chest aches, my stomach knots . . .
because I'm trying to protect you from my tears.
Then we both hurt . . . me, because my pain is held inside, a shield against our closeness . . . and you, because suddenly we're distant.
So please, take my hand and see me through my tears . . . then we can be close again.

(Reprinted with permission from Kelly Osmont, MSW, LCSW, a Psychotherapist, Certified Death Educator and National Speaker. She is also the co-author of 'Parting is Not Good-bye and author of *More Than Surviving: Caring For Yourself While You Grieve, and What Can I Say? How To Help Someone Who Is Grieving: A Guide.* Nobility Press, 811 NW 20th Ste. 103, Portland, OR 97209-1405. Phone: (503) 221-4243.)



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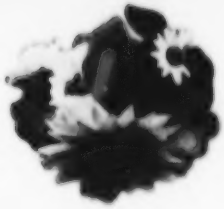

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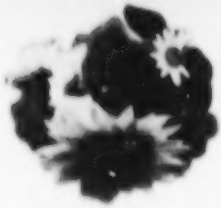

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